

Patient and Family Summit

June 27-28, 2025



Oxalosis &
Hyperoxaluria
Foundation

Meeting Agenda

Nashville, TN

Embassy Suites by Hilton Nashville
Downtown, 708 Demonbreun Street
Nashville, TN 37203





FRIDAY

Registration/Information

3rd Floor / Meadow D Foyer

1:00 PM Please stop by the Registration Desk to check in and pick up your welcome information, agenda, t-shirts, and name badges.

State of the OHF

3rd Floor / Ballroom Meadow D

2:00 *Kim Hollander, Oxalosis and Hyperoxaluria Foundation & Tiffany Reid, Patient Advocate*
Hear from Leaders in the OHF and OHF community about 2025 and the future of hyperoxaluria.

Icebreaker

3rd Floor / Ballroom Meadow D

2:30 *Kim Hollander, Oxalosis and Hyperoxaluria Foundation*
Connect with your fellow attendees!

Childcare is available, inquire at registration if you are interested!

Check out the young adult (YA) Track for the OHF Patient and Family Summit!

YA

Nashville Scavenger Hunt: Monuments and Majesty

3rd Floor / Meadow D Foyer

2:30 Embark on an exciting journey learning about Nashville's rich history with the "Monuments and Majesty" scavenger hunt! Explore iconic landmarks, uncover hidden stories, and discover the grandeur of Nashville's monuments. From the former farmland turned fairgrounds to Tennessee's historical gems, this scavenger hunt combines culture, fun, and friendly competition. It's a fantastic way to immerse yourself in the city while building connections with fellow attendees! Runs until about 5:00 pm.

Deciphering Your Diagnosis: What Every Hyperoxaluria Patient Needs to Know

3rd Floor / Ballroom Meadow D

3:00 *John Lieske, MD, Mayo Clinic*
Whether you were diagnosed this year or have been navigating the diagnosis for decades, this session will provide essential information about hyperoxaluria. Learn about the condition, treatment options, and how to effectively manage your health moving forward.

Break and Exhibitor Tables

3rd Floor / Meadow D Foyer

3:15

People Like Me

3rd Floor / Choose Your Breakout Session

3:35 *Kelley Coleman, Patient Advocate*
What it's Like to Care for Someone With a Rare Disease
This breakout session invites caregivers of individuals with hyperoxaluria to discuss the challenges they've faced in the past year. Connect with others who understand the unique demands of caregiving, share experiences, and offer insights for better managing the journey. This is an opportunity for support, validation, and constructive conversation.

Angela Baggett, RN, Boston Children's Hospital

What it's Like to Live with Hyperoxaluria

This breakout session offers individuals with hyperoxaluria the opportunity to share their experiences, challenges, and triumphs over the past year. Participants will connect with others facing similar health and emotional hurdles, providing a space for mutual support and constructive discussion. Share, listen, and learn from those who truly understand the journey.

Transforming Hyperoxaluria Care: The Future of the OHF Registry

3rd Floor / Ballroom Meadow D

4:30 *Leah Knoke, Mayo Clinic*
Learn how the OHF Registry is advancing hyperoxaluria care through research and patient data. This session will cover the importance of registry participation, how to keep your records up-to-date, and the reconsenting process. Discover how your involvement helps drive better treatments and outcomes for the hyperoxaluria community.





FRIDAY

Day One Wrap-Up

3rd Floor / Ballroom Meadow D

4:50

Kim Hollander, Oxalosis and Hyperoxaluria Foundation

Welcome Reception and Exhibitor Tables

3rd Floor Floor / Ballroom Meadow D

5:00

SATURDAY

Don't miss breakfast on the 4th floor
at 7:00 am and included in your stay!

Registration/Information

3rd Floor / Meadow D Foyer

8:30 AM

Please stop by the Registration Desk to check in and pick up your welcome information, agenda, t-shirts, and name badges.

Summit Keynote

3rd Floor / Ballroom Meadow D

9:00

Kevin Koo, MD, MPH, Mayo Clinic

Join Dr. Kevin Koo for a powerful keynote highlighting the strength, resilience, and empowerment of patients living with hyperoxaluria. Dr. Koo will share inspiring insights on overcoming challenges and the importance of patient advocacy in driving change. This session is a celebration of the remarkable courage and determination of the hyperoxaluria community.

YA

Words of Worth

3rd Floor / Riverbed C

9:00

Believe Team

Session continues through about 12:00 pm.

Icebreaker

3rd Floor / Ballroom Meadow D

9:20

Kim Hollander, Oxalosis and Hyperoxaluria Foundation

Connect with your fellow attendees!

Basic Research is Not so Basic: Strides in Research and Hyperoxaluria Representation

3rd Floor / Ballroom Meadow D

9:30

Todd Lowther, MD, PhD, Wake Forest University School of Medicine, John Knight, PhD, University of Alabama Birmingham

Dr. Lowther and Dr. Knight will provide accessible insights into current basic research initiatives and OHF's support for ongoing research efforts and will highlight this year's grants, cross-kidney collaborative initiatives, and the importance of participation in advancing the field. The session will also emphasize the significance of representation in research discussions and the impact of advocacy at key meetings and boards.

Therapeutic Frontiers: Exploring Mechanisms and Investigational Approaches in Hyperoxaluria

3rd Floor / Ballroom Meadow D

9:50

Matthew Breeggemann, MD, University of California San Francisco

This session will cover the latest therapeutic advancements in hyperoxaluria, focusing on current mechanisms and approaches of therapies under investigation.

Practical Care and Treatment: Empowering You to Advocate in Urology

3rd Floor / Ballroom Meadow D Panel Session

10:05

Panelists: *Greg Tasian, MD, Children's Hospital of Philadelphia, Kevin Koo, MD, MPH, Mayo Clinic, David Duong, MD, PhD, Urology Associates of Nashville; Moderator: Kristina Penniston, PhD, University of Wisconsin-Madison*

Urology experts will address common concerns in managing hyperoxaluria, including the use of stents, radiation exposure over time, and the impact of multiple procedures. Patients will learn how these treatments impact kidney health and gain tools to better communicate with their urologists about their care and treatment options.

Break and Exhibitor Tables

3rd Floor / Meadow D Foyer

10:45

SATURDAY

Building an Engaged Community: OHF Programs for Connection & Advocacy

3rd Floor / Ballroom Meadow D

11:05

Sam Ekdorn, Kristi Ouimet, Rabia Zhen, Patient Advocates

Highlighting Share Your Story, Social Media Campaigns, and the Buddy Program as pathways for support, empowerment, and engagement in the hyperoxaluria community. Sign up at the meeting and make a commitment!

Hyperoxaluria Uncovered: Nephrology Insights Live

3rd Floor / Ballroom Meadow D Panel Session

11:25

Panelists: John Lieske, MD, Mayo Clinic, David Sas, DO, MPH, Mayo Clinic, Matthew Breeggeman, MD, Michelle Baum, MD, Boston Children's Hospital, Kristina Penniston, PhD, University of Wisconsin-Madison; Moderator: Kevin Koo, MD, MPH, Mayo Clinic

A live panel featuring expert nephrologists and a dietician answering key questions about hyperoxaluria, offering in-depth insights into diagnosis, treatment, and ongoing research.

Words of Worth Presentation

3rd Floor / Ballroom Meadow D

12:05

Believe Team

Lunch and Exhibitor Tables & Group Photo

3rd Floor / Meadow D Foyer

12:35

Expanding Horizons: The Future of the OHF Care Center Network

3rd Floor / Ballroom Meadow D

1:30

John Lieske, MD, Mayo Clinic, Michelle Baum, MD, Boston Children's Hospital, Matthew Breeggemann, MD, University of California San Francisco

Updates on the growth of the OHF Care Center Network, welcoming new centers, strengthening support and enhancing patient care within the PH community.

Inside the Trial: Empowering Patients in Clinical Research

3rd Floor / Ballroom Meadow D

1:40

Madeline Heaney, Center for Information & Study on Clinical Research Participation

A deep dive into the stages of clinical trials, highlighting how patients can actively engage in the process, from initial design to outcomes. This session will explore the vital role patients play in advancing research and the ways they can help shape the future of PH treatments.

I can, I will, I am: How I am Making a Difference

3rd Floor / Ballroom Meadow D Panel Session

2:00

Panelists: Kelly Gilligan, Muhammad Faraz Khaliq, Tiffany Reid, and Sam Ekdorn, Patient Advocates; Moderator: Gregory Tasian, MD, Children's Hospital of Philadelphia

Individuals share their personal journeys, the strength they've found through their experiences, and how they are making a difference through advocacy. Participants will offer valuable insights, wisdom, and stories of resilience that empower and inspire others in the PH community.

Break and Exhibitor Tables

3rd Floor / Meadow D Foyer

2:30

Advocacy and Me

3rd Floor / Choose Your Breakout Session

2:50

Kendly Jones, EveryLife Foundation

Advocacy & Me: Finding Your Voice, Making an Impact

Exploring personal advocacy and practical ways to drive change in the PH community.

Kelley Coleman, Patient Advocate

Navigating School Systems: Access, Accommodations & Advocacy

Guidance on securing support, accommodations, and resources for students with PH.



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SATURDAY

Hyperoxaluria and Me

3rd Floor / Choose Your Breakout Session

John Lieske, MD, Mayo Clinic, Sonia Fargue, MD, PhD, University of Alabama Birmingham

Emerging Horizons: Updates on Enteric Hyperoxaluria

Exploring progress in understanding EH and advancements in disease management.

3:30

David Sas, MD, MPH, Mayo Clinic, John Knight, PhD, University of Alabama Birmingham

Advancing Knowledge: The Latest in PH1 Research & Care

Examining the mechanisms behind PH1 therapeutics and progress in treatment development.

Todd Lowther, PhD, Wake Forest University School of Medicine, Michelle Baum, MD, Boston Children's Hospital

PH2 & PH3: Unlocking New Insights

Discussing current understanding of PH2 and PH3 and the evolving pipeline of small-molecule therapeutics.

Reflection & Resilience

3rd Floor / Ballroom Meadow D

4:10

Kim Hollander, Oxalosis and Hyperoxaluria Foundation

Exhibitor Tables

3rd Floor / Meadow D Foyer

5:00

Farewell Dinner & Line Dancing Lesson

30th Floor / The Overlook

6:00

Event Supported By

Leader



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